Equality & Diversity within Shared Lives

SharedLivesPlus
THE UK NETWORK FOR SMALL COMMUNITY SERVICES

Shared Lives Plus – the Organisation

Shared Lives Plus is the UK network for small community services. Our members deliver very small-scale, family-sized or community-based care and support solutions for older and disabled people. Our members are Shared Lives carers and workers, along with Homeshare programmes.

Like our members, Shared Lives Plus is small, but ambitious. Our aim is to see safe, high quality family and community based support become the go-to option for care, support and inclusion. Our members use ordinary family homes and the extraordinary power of families and friendships to challenge assumptions about what is possible, not only in social care but increasingly also in healthcare, young people's support and offender rehabilitation.

This year, Shared Lives Plus has grown along with the sectors we represent, but we want to accelerate the rate at which our members can reach more adults of all ages with their life-changing work.

Equality & Diversity within Shared Lives

Introduction

Shared Lives can be a fantastic way for people from all communities and groups to contribute to and receive care and support which matches their particular needs.

Shared Lives Plus is the representative body for the Shared Lives sector across the UK. We are committed to promoting equality and embracing diversity in our own work, and we support and enable our members to do the same.

This is a short report that was compiled in response to feedback from our members in which they felt that the equality and diversity agendas were not given the prominence they deserved, both by Shared Lives Plus and by the Shared Lives sector in general.

It gives a very brief outline of our organisation and of the Shared Lives model. It then details issues and barriers relating to the promotion of equality & diversity, as well as examples of good practice in overcoming some of these barriers. Lastly, it details a number of case studies that exemplify how Shared Lives is working to promote equality and embrace diversity in people's daily lives.

Brigita, Newham

Brigita is an older lady from Eastern Europe, who had been living in unsuitable overcrowded shared accommodation, and had been working in hotels. After having a stroke, Brigita was given an initial six week respite placement with her local Shared Lives scheme, with the idea that she would then be well enough to present as homeless. This was then extended to a three month placement.

Every time scheme staff meet her they are moved by hearing her speak about how grateful she is to her Shared Lives family for the support and friendship they give her. For her, as an isolated woman in this country, who speaks very little English, the scheme believe that it has been a really important part of her recovery, that she was able to live as part of a family, and not have to worry about anything but getting better.

The Shared Lives model

In **Shared Lives**, an adult (16+) who needs support and/or accommodation moves in with or regularly visits an approved Shared Lives carer, after they have been matched for compatibility. Together, they share family and community life. In many cases the individual becomes a settled part of a supportive family, although Shared Lives is also used as day support, as breaks for unpaid family carers, as home from hospital care and as a stepping stone for someone to move towards independence.

The outcomes can be startling, with people reporting feeling settled, valued and like they belong for the first time in their lives. They also get involved in clubs, activities and volunteering and in many cases, find a route into employment.

Shared Lives is used by people with learning disabilities, people with mental health problems, older people, care leavers, disabled children becoming young adults, parents with learning disabilities and their children, people who misuse substances and (ex) offenders.

There are already approximately 8,000 Shared Lives carers in the UK, recruited, trained and approved by 152 local schemes, which are regulated by the government's social care inspectors, who in 2010 rated Shared Lives as being twice as likely to be 'excellent' as all other forms of regulated care.

Shared Lives is also significantly cheaper than other forms of care: on average £26k a year cheaper for people with learning disabilities and £8k for people with mental health issues. Figures from care inspectors suggest it has perhaps the best safeguarding record in social care.[1]

Diversity within Shared Lives and promoting equality

The Shared Lives model is particularly successful in promoting equality for disabled people, through enabling people who use the service to access 'mainstream' opportunities.

In our 'First Time Survey' of 80 Shared Lives carers (supporting between 500 – 550 people[2], through short breaks and longer term arrangements), a quarter of service users had joined a club or group which is not specifically for disabled people for the first time. These findings reflect extensive anecdotal evidence and are further backed up by the results from inspections, which report that Shared Lives schemes are consistent on outcomes such as living an 'ordinary life'.

While other forms of social care support may find it more difficult to support people to develop and maintain relationships, Shared Lives reports exceptionally strong outcomes in this area.

Hilary, Powys

Hilary was an 84 year old woman living on her own in a small rural community. She had been living with dementia for some years and was receiving informal support from Robyn, who would visit twice a day to make sure that she had taken her medication, had some food, lit her fire etc.

Over the past winter, Robyn was becoming increasingly concerned as Hilary was letting her fire go out, not eating regularly, becoming more disorientated and struggling with her personal care. Robin alerted social services which resulted in her being trained and approved as a Shared Lives carer with the Powys Shared Lives Scheme. Hilary had been a visitor to Robyn's house for over 50 years and had known Robin's husband all his life and Robyn for over 13 years. She moved in with Robin and the familiarity meant that she felt at home straight away.

As she did not have to move away to receive support, Hilary has been able to keep all of her friendships and connections. Her Care Manager and family have said that she has been doing really well.

[1] Investing in Shared Lives 2013, RSA, Shared Lives Plus, Macintyre, Community Catalysts

[2] First Time Survey, Shared Lives Plus

Roy, Falkirk

Community Care examined a breaks service in Scotland, under the headline Helping Dementia Patients with a wider family circle. “Celia is generosity itself. She and Roy get on like a house on fire,” says Mary Willis about the relationship between her husband and their Time to Share carer, Celia.

“She includes Roy in everything the family do; he gets a front seat at the Highland shows they go to. Her husband is a good musician and Roy plays the African drums so there is a connection there. Celia takes him out a huge amount and he is treated like one of the family.” Roy currently visits Celia three or four times a year, and although Mary says this may increase as she gets older, she adds: “I hope to put off residential care forever.” Full story: http://www.communitycare.co.uk/Articles/2010/10/28/115701/good-practice-time-to-share-scheme-for-dementia-patients.htm

Careful matching between Shared Lives carers and people who need support is one of the key components of this model of care. Matches aim to find people who are compatible with each other. Sometimes people are looking for Shared Lives carers of the same background or faith. However, there are examples of successful inter-cultural and inter-faith matches which challenge assumptions about who is compatible. For example, we know of one Shared Lives carer who is Sikh and the two men who share her home are Muslim and Hindu. After some initial concern from the men’s families, they are now really happy to see how the Shared Lives carer ensures that everyone’s faith is encouraged and respected.

Khalid, London

‘Khalid’ is a younger man who has had his third stroke, and was unable to return to live in his own flat by himself. The social worker was keen that he didn’t have to go to a nursing home, at such a young age. We were able to match him with a Shared Lives family originally from the same city in Pakistan as his own family. This has been really helpful for his family, as this has been a difficult situation for them to come to terms with. Being able to talk to the Shared Lives carers in their own language, and feel that they are offering support that is similar to the support that his family would give him if they were able to. Also it meant that he is able to maintain his previous social circle, with his friends visiting. He is keen to return home and live on his own again, and we are working towards this as a long-term goal.

In some areas, certain ethnic minority groups have traditionally not engaged with social care or health services, with the family and their wider community meeting many of these needs. Understanding the traditions and way of life in these communities is key to being able to successfully engage with them.

What we want to do better

As an organisation and a sector, we are committed to:

1. Supporting local schemes to gather better information about the diversity of people using and providing Shared Lives

Shared Lives Plus does not hold detailed data on which to analyse equality and diversity issues and trends, and is reliant on gathering such data from its member schemes. Shared Lives Plus has recently carried out an extensive survey of our member schemes within England, and this survey has given some useful demographic data, particularly for the scheme workforce and for Shared Lives carers. It has however still proved a challenge to obtain diversity data for people using Shared Lives services – as schemes have generally not gathered such information.

Shared Lives Plus intends to improve the quality and scope of data on which to analyse diversity and equality trends and will do so by carrying out annual surveys of our members in each of the UK countries.

Government and similar agencies' statistics on demographic trends, etc., tend not to specifically single out Shared Lives as a distinct form of support, which again can make analysis difficult. For example the ESAY return is published annually by the Scottish Government, giving statistics about people with Autism and learning disabilities, but it incorporates Shared Lives with 'other forms of support'.

The data that is generally gathered about service users, tends to be predominantly about the nature of their main support needs (e.g. learning disability, mental ill health, etc.) and does not 'drill down' to look at a person's other diversity characteristics, such as ethnicity, sexuality, etc. Shared Lives Plus has gathered some excellent case studies, which demonstrate good practice in promoting equality, but this information is qualitative and does not allow for quantitative analysis.

Traditionally Shared Lives Plus has focussed its efforts on supporting the work of our members, namely Shared Lives carers and scheme workers. We have however identified that we must do more to further empower and give a voice to the people who use Shared Lives services. In order to do this, we have recently commissioned a User Led Organisation, who will work with our members, to ensure that service users are much more actively involved in the way services are planned and delivered.

2. Support areas to learn from good practice elsewhere in the UK network

Our own 2012 survey of Shared Lives carers across the UK[3] found, that almost 91% of people classified themselves as white British, and 8.4% as being non-white. However, in some parts of the UK, the majority of carers currently come from a white ethnic background. A recent survey of Shared Lives in Wales found that only 0.6% of carers came from a BME ethnic background, which is significantly less than the number of people from a non-white ethnic background that would be present in the general population (6.8%[4]).

In contrast, the Haringey Shared Lives scheme[5] found that only 28.8% of their carers classed themselves as white British – compared with the 2011 Census analysis of the general population in that borough, where some 34.7% of people were recorded in this group[6], suggesting that the scheme needs to work harder to recruit white British Shared Lives carers.

[3] Carer Survey 2012, Shared Lives Plus

[4] Shared Lives in Wales 2013, Shared Lives Plus

[5] Carer Survey, Haringey Council Shared lives Scheme

[6] UK Census, 2011, detailed in Haringey Council's website

Sonia, Bradford

Sonia was referred to her local Shared Lives services about a year ago. She is 57 years of age and came into the country about four years ago from Pakistan to live with her brother and his family.

It was a real culture shock for Sonia to come and live in a big city like Bradford as she was brought up in a small village in Pakistan. It was assessed that it would not be suitable for Sonia to attend the regular day centre services due to her mental health; she was very withdrawn and suffered from anxiety and panic attacks.

Shared Lives were able to match Sonia to a young woman from the same religious and cultural background. The Shared Lives carer also spoke the same dialect which is not very commonly spoken in Bradford.

The Shared Lives carer takes Sonia out to different places in Bradford. Sonia's sister-in-law and her social worker have reported there have been great improvements in Sonia. She is now happy to go out and about in the community which she would not have done two years ago.

It has really benefited Sonia to have a Shared Lives carer who speaks the same language and is of the same ethnic background.

3. Support our members to identify and campaign on issues which affect the financial sustainability of Shared Lives

The data collected by Shared Lives schemes does not generally record details of the socio-economic status of Shared Lives carers. In our 2013 Welsh survey however, one scheme pointed out that Shared Lives carers from poorer socio-economic backgrounds are disadvantaged by the recruitment process, as they are required to bear certain expenses (safety certificates, adaptations) and there is a significant waiting period until they are approved. The precarious nature of Shared Lives arrangements also means that Shared Lives carers cannot rely on a steady income and there is a risk that Shared Lives carers with lower household incomes drop out.

4. Explore with schemes how to attract more people from under-represented groups to become Shared Lives carers, including men, young people and disabled people.

In our UK members' survey, 37% of Shared Lives carers were men and this proportion was slightly lower in the Welsh survey, suggesting that underrepresentation of men is an issue which Shared Lives shares with much of the care sector.

Our 2012 Shared Lives survey calculated an average age of 56 for carers. In the same Welsh survey, over half of the Shared Lives carers were older than 55. Shared Lives support requires a high level of commitment and financial stability from Shared Lives carers and for carers offering long term support to have at least one spare room. People over 55 are most likely to find themselves in a position to be able to commit to Shared Lives and to have the necessary space.

However, the overrepresentation of people over 55 raises concerns about the sustainability of arrangements over a long period of time, particularly for younger service users.

Our own 2012 survey recorded only 4% of Shared Lives carers who would class themselves as disabled. This is significantly lower than the number of people in the general population who would be classed as having a disability, long term illness or impairment (16%)[7].

[7] Disability facts and Figures (2012), Office for Disability Issues

Data has been particularly difficult to gather in terms of people's sexuality – the most common reason given for this would seem to be reluctance by the carers to divulge such information.

Also, this information has not been traditionally gathered by schemes or by ourselves, and this may also explain the lack of returns in this particular area of diversity monitoring.

Debs & Dave, Derbyshire

Nathan, 37, works in Derby City Council's employment team supporting people with learning disabilities and James 33, a bank worker, are part of the council's Shared Lives scheme. The couple, who married in 2006, support Debs and Dave, who live with them as well as another lady who comes to their house for short breaks. James says, "We were conscious for quite some time that, although we were having lovely lives doing what we wanted when we wanted, we were not giving anything back."

James said: "Debs and Dave both say they want to live on their own eventually and, to do that, you need to be able to cook and clean for yourself and budget your money. That is why, from Monday to Friday, we have things they do like ironing, to get into that routine." When asked about the rewards of being a Shared Lives carer, Nathan says, "It is the simple things like seeing them get the bus without needing anyone to help them. It is seeing their confidence grow."

However, where we have managed to gather data on carers sexuality, such as our own 2012 survey, there are positive signs in terms of diversity, with 5.4% identifying themselves as gay, lesbian or bisexual. This is significantly higher than UK government statistics for the general population which records only 1.5%[8].

There are often barriers to engaging with some minority communities within an area, A solution to this barrier can often be by engaging with community leaders within groups to disseminate information within that group as the leaders are widely respected by them.

Haringey - Engagement with the Greek/Cypriot Community

Haringey is a socially, ethnically and culturally diverse borough in North London. Historically there is a large Greek Cypriot community living in Haringey who have started to use the services provided by Haringey Social Services.

For a number of years, the Scheme was unable to respond to requests from service users/families from the Greek community, to provide culturally specific placements. This was because they had no carers from this particular community.

To address this, the Scheme was interviewed on Greek radio (the interview was translated simultaneously into the Greek language). On the back of this they still did not recruit any Greek/Cypriot carers. As a result the scheme followed up the interview with posters in the Greek language, again with no success.

When a job share opportunity arose within the Shared Lives team a Greek speaker was recruited. This opened the opportunity to further approach the Greek/Cypriot community.

[8] Integrated Household Survey (2012), Office for National Statistics

Setting up a stall and holding an information meeting within a Greek/Cypriot community centre it became apparent that the community found the concept of another family looking after someone who was not related, totally alien.

The community felt that no one would call on outsiders to care for a relative. (Relatives would always look after someone within the family).

From these discussions the scheme altered the way in which it targeted this community and tended to talk predominantly to people from the 2nd generation and further worked with the community to open up areas where they could access statutory support.

The scheme now has 3 Greek Cypriot carers 2 first generation 1 second generation.

Equality & Diversity Action Plan

Issue/Area of Need	Required Action	Timescale
Traditionally most Shared Lives schemes do not capture or hold equality & diversity information on people who use their services	Carry out an annual survey of schemes to capture this data, awareness raising with schemes to raise understanding of the importance of the data. User led org project raising profile and involvement of people who use SL. Etc.	Initial surveys carried out in 2013 of English and Welsh schemes. Repeat in each of the UK countries on an annual basis
	Roll out learning from areas of good practice	
	National recruitment campaign	
	Community connecting approach to engage with and recruit SL carers from all section of the community	

Appendix

Shared Lives Carer's Testimonies
from our 'First Time Survey'

"One of my ladies was terrified to go outside. She can't read, write, tell the time and has no concept of time. She had never travelled alone. She now accesses the public bus service herself alone on foot, crosses busy roads, gets on the right bus and gets to college alone and returns alone. This lady is blind in one eye and has a cataract in the other.

She has made lots of friends of her own. She has a voluntary role in a cafe taking money and orders as well as making food and clearing away. My other lady also works in a voluntary role in a cafe and does the same, taking orders, money and making food as well as cleaning away. Both ladies have been with me for over a year. Both have now experienced a "normal", "loving and caring family environment", something they had never experienced before."

"By passing his test on an electric wheelchair, for the first time in his entire life, he is in his 50's he was able to go off ON HIS OWN unaided at a show in a showground to look at things he wanted to look at and come back to us when HE is ready."

"I have cared for the same person for the past 13 years. A few years ago, after my daughter's first communion party, my service user said he would like to make his communion and have a big party like that - it transpired that there was no record of him being baptised...in the end he was baptised, received Holy Communion and confirmed as an adult at the Easter Vigil. Following the event, he had a big party and received lots of presents/ money and lots of congratulations/well wishes. Our Parish Priest was amazing in all this.

I supported the service user through the preparation programme and a relative of mine was delighted to stand as his godfather. To this day, my service user talks of this as a big event in his life. He attends Church every Sunday, sings in the choir and goes to Lourdes each year. Through the Church, he has become a member of the Catholic Fellowship and has been to a number of places with them - France, Spain, Gibraltar and the US as well as Wales and Cornwall."

"When L came to live with us, he was taking a lot of anti-psychotic drugs (mainly because of his behaviour towards other people) he also suffered badly with incontinence. Since February this year, he is no longer on [drug X], and his [drug Y] has been reduced. The cause for his incontinence has been diagnosed as prostate cancer, which he probably had for several years prior to living with us."

"it has helped their journey from an inmate in a mental institution to a free, active and happy life. A person who now has a girlfriend, regular contact with his family and enjoys life as any senior citizen should - he is happy.

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